Committee Member

Dear Member,

An Act Concerning Aid in Dying for Terminally III Patients (HB 5898) was introduced by Rep. John Steinberg and is being considered by the Joint Committee on Public Health.. This legislation would allow mentally capable, terminally ill adults with six months or fewer to live the option to request and receive a doctor's prescription for medication they can decide to take to die peacefully if their suffering becomes unbearable. As your constituent, I ask that you support this important legislation.

For me, this issue is personal.

Four years ago, in her final stage of Alzheimer's Disease, my 85 year old mother literally choked to death. When we got the call from my father who cared for her at home, my two sisters who live locally, and I, who live further away, rushed to be by her bedside. Finally, we assumed we'd be witness to her peace and thankfully, in her own bed.

Our dear mother who had lost everything to this horrific disease for nearly ten years would finally and mercifully be at rest. But her final moments were far from peaceful. I live an hour and a half away and didn't make it in time to see her take her final breaths, but I am grateful and I know my mother would be too. My sisters who did make it are so haunted by what they witnessed; working to offer her comfort for

45 minutes, while she gasped through minimal doses of morphine administered by a Hospice nurse-morphine that did little to calm her breathing, or more swiftly and humanely end her obvious finale of suffering.

The onset of this seventh and what was deemed terminal phase of her illness by Hospice last November, came piece by piece over a decade.

But there is always something to be grateful for. Our mom, who lost nearly all of her abilities, knew her family at times, right to the end. Yes it was both a gift and a curse, for her and us- to be aware. She could, occasionally, speak and would find what was left of her voice, begging us to help her, "I don't want to do this anymore," she would cry. "Please help me." Unless you have ever been witness to someone you adore who is emotionally and physically suffering from a terminal illness like Alzheimer's, you cannot imagine the torment I felt each time I walked out the door of my childhood home, leaving her, on the couch, in a fetal position, no longer able to stand, swallow normally, or control any of her bodily functions. I pleaded with God to take her. Mercifully allow her to pass away from something like pneumonia or another infection, before she makes it to the terminal phase, I would pray. But that never happened.

Instead she spiraled into what I know for her was a tormented abyss.

When I got the news this past fall, that Hospice had qualified her under guidelines that stated she could likely pass away in six months, I was relieved for her and for our family. I assumed we would gather together by her bedside in the near future, before, what I had read, could be her death by choking. I envisioned us holding her hand and seeing her through to what was her inevitable death, in peaceful, compassionate moments. I naively assumed that Hospice had the ability and legal right to manage those final moments, ending her suffering, with the only drug at their disposal-morphine. As you have heard, that wasn't the case and I've since heard the same from many of my friends who have also lost parents. Two weeks later, my father who was married to my mother for 64 years and as I mentioned cared for her in their home, gave up and told all four of his daughters, he no longer wanted to live without her. We all believe he was willing himself gone because he suddenly and surprisingly had a stroke that fully

compromised the left side of his body and his ability speak. He was also diagnosed with a severe MRSA infection. Over the course of a day in the hospital, he rallied somewhat from the stroke and regained his voice, now weakened, pleading with the hospital staff to end his suffering. He did not want to perish, now incapacitated, for what could be months or years in a nursing home bed. The doctor told him that in the past, his stroke and infection were examples of how elderly people died of what was called natural causes. She told him she could stop all treatment and allow him his ultimate choice. We were once again relieved, although naively thinking that our other parent would have the peace he was seeking, even though it was just two weeks after losing our mother. Once again the only route available to his end was Hospice. They qualified him, stopped all antibiotics for the infection and began a morphine drip. I sat by his bedside for four days, as he appeared to drown in his bodily fluids, choking and gurgling before my eyes; his face nearly purple and at times contorted, as nurses suctioned his throat and mouth, trying to offer relief from what was obvious distress. When I noticed, after the third day of this slow decline, that he, had turned yellow, I assumed his liver was failing. The doctor stood by his bed with me and concurred; saying it wouldn't be long now. She examined him and said he'd go within a few days. I pleaded with her to just administer something to bring him to a peaceful end. It was evident. There was no turning back. She told me that was illegal and that this was his process of death and that he must go through it. I was speechless.

He did finally pass away alone at 2am without any of his family by his bedside. As I said, we had been informed by the Hospice doctor, that death was imminent but that could be within three more days. My sister and I were exhausted from the vigil and left him for our much needed sleep. And so, he died alone; a memory that will forever break our hearts. With a dignified death and compassionate ending we could have more humanely seen him through in a loving manner, holding his hand and getting him where he wanted to be-with our mother once again.

Seven years ago my elderly father-in-law who suffered from severe COPD took his own life in a horrific solitary event that spurred me to begin my journey supporting Compassion and Choices and death with dignity laws. He was a brilliant and sensitive man, whom we all loved and respected beyond words, who was told by medical professionals that he was terminal- that there was nothing more to be done for him, other than send him home with an anti anxiety prescription, one that may help when his breathing became labored to the point of panic. It did nothing for him as he lay awake at night gasping for breath. And so after months of struggle, he eventually planned suicide; trying desperately to spare himself and his wife and family what lay ahead, with no peaceful or merciful solution offered or in sight. He waited until she departed from the house for a shopping trip with my sister-in-law, left my mother- in- law a note, called 911 and told emergency personnel, he would use a hand gun; his only means of swiftly ending his suffering, without implicating anyone, and to please be sure his body and all signs of his death were eliminated from the patio before their return.

He got his wish. He was gone before they got home and yet we were told he did not die instantly. Our family is still reeling from what he saw, as the only alternative to end his suffering. We relive what could have been his peaceful ending with us by his bedside, honoring the wonderful man that he was, seeing him through to a compassionate end- not the one that he was forced to desperately seek out in such a violent final act that defies what he or any family of a terminal patient should endure.

I struggled with a final message, wrapping up what I have shared with you. I can only come up with one poignant thought. How could any of us who love, possibly speak against aid in dying for terminal patients, deemed so by not one but at least two medical professionals? How could any of us who love or believe in a merciful God, not wish for our own family members, their right and choice to end suffering, which has been medically qualified as inevitably fatal? There could be no abuse of a law which states just that. Keep in mind too. It is a choice. Look to the Oregon Death With Dignity Law which has been in place since 1997.

There have been no abuses. And there would be no coercion or forcing an individual to make the decision in this state either. The time is now for Connecticut residents to bring legislation to loving families and to fruition.

Seven states and the District of Columbia currently authorize medical aid in dying. Rep. Steinberg's legislation empowers terminally ill individuals to determine their end-of-life options. That power is in the in the hands of the patient, not the medical provider -- a critical safeguard that provides Connecticut residents with a transparent, regulated medical practice that ensures terminally ill individuals are protected.

Please support HB 5898: An Act Concerning Aid in Dying for Terminally Ill Patients.

Sincerely,

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